# NCBDDDannualreport2011

National Center on Birth Defects and Developmental Disabilities • Centers for Disease Control and Prevention

## **Hearing Loss in Children**

# Ensure that all Newborns are Screened and Assessed for Hearing Loss and Receive Appropriate Intervention

#### What Is the Problem?

- Each year, more than 12,000 babies are born with hearing loss; most have two hearing parents.
- When an infant has a hearing loss, it is cause for immediate attention. This is because language and communication skills develop most rapidly in early childhood, especially before the age of three. When hearing loss goes undetected, children are delayed in



- developing language and communication skills. Early intervention is an effective way to help infants and children develop communication skills as soon as possible in their lives.
- Universal screening is only the first step—the next steps are confirming hearing loss and then receiving intervention services.
- In 2009, 45% of newborns not passing their hearing screening could not be documented as
  having received the follow-up testing needed to make a diagnosis, or being enrolled in early
  intervention services. Adequate data systems and tracking procedures are needed so that
  families, health care providers, and programs can follow the progress of children identified with
  possible hearing loss.

#### What Do We Know?

- Hearing level can vary greatly among children and can be caused by many things. <u>In the United States</u>, 1 to 3 children per 1,000 are born with hearing loss each year. The differences in hearing level can range from mild to profound loss.
- Genetic factors are known to be the cause in about 50% of situations where babies have hearing loss. Illnesses, injuries, certain medicines, and loud noise levels can also cause children and adults to lose hearing.

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- Over 97% of all newborns in the U.S. are now screened, a tremendous success. The next challenge is ensuring that those newborns who do not pass the screening receive recommended follow-up services.
- Early intervention is one of the best ways to help children with hearing loss. The earlier children with hearing loss are diagnosed and start getting services, the more likely they are to reach their full potential. Ideally, families are able to choose from a full range of early intervention options and receive support to succeed. Awards and technical assistance from NCBDDD's Early Hearing Detection and Intervention (EHDI) program have supported state efforts to:
  - Share information across jurisdictions to match information about children born in one state but living in another.
  - Develop comprehensive reporting systems to improve the amount, quality, and timeliness of data from clinicians and other health care professionals to follow children.
  - Integrate EHDI data collection with other child health data systems to help account for all children.

#### What Can We Do?

- Support the national EHDI 1-3-6 benchmarks, which include hearing screening no later than
  age 1 month, diagnostic audiologic evaluation no later than age 3 months (for those infants not
  passing the screening), and enrollment in early intervention no later than age 6 months (for
  those identified with a hearing loss).
- Continue development and implementation of EHDI tracking systems in 52 states and territories. Provide technical assistance to all states and territories.
- Look for potential causes and risk factors for hearing loss, and identify causes and solutions
  for those infants not following-up with the testing needed to make a diagnosis, or being
  enrolled in early intervention services.
- Improve information systems to help states:
  - o Generate timely statistics.
  - Improve service delivery.
  - Measure changes related to policy and program changes.
  - o Address other issues that are important to state, local, and national policymakers.



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 Develop and implement standards for interoperability with electronic health records (EHRs) on infant hearing loss identification and services.

### **Accomplishments**

- With over 97% of newborns in reporting jurisdictions now screened for early hearing status, the EHDI program is focusing on what happens to infants who did not pass the hearing screening—the loss of infants to documented follow-up.
- Awarded competitive grants to 52 states and territories for EHDI tracking systems that allow tracking of services for infants.
- Four selected states are taking part in a pilot project to improve quality and timeliness of EHDI data.
- Started a sentinel surveillance model in select states to provide more consistent and timely information on loss to documented follow-up and identify areas for continued improvement.

### Looking to the Future

- Enhance state and territorial EHDI tracking systems so programs are better able to (1) accurately assess the number of infants who receive appropriate, timely follow-up services and (2) document improvements in infant/family outcomes.
- Obtain a better understanding of health disparities and service gaps within and among different geographic, socioeconomic, race/ethnicity, and gender groups on early intervention services.
- Promote the adoption of national data coding standards by EHDI stakeholders in order to take advantage of electronic health record interoperability.

### Notable 2011 NCBDDD Scientific Publications (Published in 2010)

- Abhyankar S, Lloyd-Puryear MA, Goodwin R, Copeland S, Eichwald J, Therrell BL, Zuckerman A, Downing G, McDonald CJ. Standardizing newborn screening results for health information exchange. AMIA Annu Symp Proc 2010; 1–5.
- Biernath KR, Montero DP, Mehl A, Toomey KE. **Universal newborn hearing screening and beyond**. Am Fam Physician 2010;81(2):124.
- Gaffney, M. Eichwald J, Grosse SD, Mason, CA. **Identifying Infants with Hearing Loss United States, 1999—2007**. Morbidity and Mortality Weekly Report; 2010; 59(08):220–3.
- White KR, Forsman I, Eichwald J, Munoz K. The evolution of early hearing detection and intervention programs in the United States. Seminars in Perinatology 2010;34(2):170–9

